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Spaces for talking: Communication patterns of children on antiretroviral therapy in Uganda

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ABSTRACT

Understanding the perspectives of children on antiretroviral therapy is very important in order to support them to live with treatment. This article describes how different social settings facilitate or constrain HIV+ children's communication regarding their health and medicines. Through participant observation and semi-structured interviews, we explored communication practices of 35 HIV+ children aged 8–17 years.

Results show that communication in homes was limited to issues about medicines and was influenced by the hierarchical structure of domestic relations, which were not conducive for communication. At the club meetings, where children were in control of the activities, the communication was more egalitarian and child centered. At the treatment centers, there were elements of both hierarchical and egalitarian communication practices. The health workers tended to be rather authoritarian, speaking mostly to adult caregivers. Efforts to control information about HIV/AIDS were evident in all the three places but were more pronounced in homes.

Children were active in using the different spaces, and in seeking information about their health and treatment. The Convention on the Rights of the Child and Ugandan National Guidelines on HIV Counseling and Testing encourage more open communication than is currently the case. Adults need support to achieve this goal.

1. Introduction

Of the estimated 1.2 million HIV infected people in Uganda, 13% are children less than 15 years (Ministry of Health Uganda, ICF International, Centers for Disease Control and Prevention, U.S. Agency for International Development, & WHO, 2012). The number of HIV+ children receiving antiretroviral therapy (ART) in Uganda rose from 17,000 in 2008/2009 to 26,699 in 2011 (Ministry of Health Uganda et al., 2012). Understanding their situations and their perspective is important in helping them appreciate why they have to take medicines even when they are feeling well. This article describes how different social settings facilitate or constrain HIV+ children's communication about their health and medicines. We examined how HIV+ children communicated with adults and with one another in homes, post-test clubs and treatment centers.

Previous studies on communication involving HIV+ children have largely focused on caregivers' and health care providers' perspectives and dilemmas with regard to disclosure of diagnosis and treatment (Heeren, 2011; Siu, Bakeera-Kitaka, Kennedy, Dhabangi, & Kambugu, 2012; Vaz, Eng, Maman, Tshikandu, & Behets, 2010) or on adolescents' disclosure practices (Michaud et al., 2009; Siu et al., 2012). Until recently, children have been mainly conceptualized as passive participants, and their role in medical communication has largely been ignored in research (Tates & Meeuwesen, 2001; Tates et al., 2002b).

A Ugandan study suggests that to ensure adherence to life-extending medications, there is need for caregivers to provide on-going support and maintain open communication with HIV+ children (Bikaako-Kajura et al., 2006). Yet studies in Uganda and in neighboring Kenya describe a domestic hierarchy in which children occupy a subordinate position that does not favor open communication (Meinert, 2009; Onyango-Ouma, 2001). Most research on HIV+ children's communication has been conducted in the developed world where both the family situations and communication patterns are different (Cahill & Papageorgiou, 2007; Tates & Meeuwesen, 2001; Tates et al., 2002b,c). Studying HIV+ children's communication about their health and medicine is of particular relevance in the Ugandan socio-cultural context, which potentially constrains children from communicating freely.

Everyday family interactions and health have been comparatively less well studied than formal areas of health communication and influence, such as the mass media, campaigns and clinician–patient communication (Bylund & Duck, 2004). Research has occurred in clinical settings where caregivers were assumed to play a central role in the communication

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process (Cahill & Papageorgiou, 2007; Tates & Meeuwesen, 2000, 2001; Tates et al., 2002b). However, little is known about HIV+ children's communication patterns in other social spaces. This study fills a gap because it also explores the nature of communication outside of clinical settings where the majority of communication and care-giving takes place.

2. Materials and methods

2.1. Study setting

The study was conducted in Jinja District, Eastern Uganda, where overall HIV prevalence was estimated at 5.8% (Ministry of Health Uganda et al., 2012). The District population was 387,573 people, of which 79% live in rural areas. The District population is very youthful, with 56% of the total population below 18 years. A tenth (11%) of these are orphaned (Jinja District Local Government, 2009). Health facilities are distributed evenly in the district. These include 49 Government facilities, 17 non-governmental organizations (NGO) and 3 Institutional (Army, Police and Prisons) facilities. At the time of the study, 6 Government and 3 NGO facilities were providing ART for children. However, recent District statistics show that the number of health facilities providing ART for children are currently 22. At the time of the study, none of the health center threes levels (HCIIIs) was providing ART but currently all eleven HCIIIs in the District are providing ART, including ART to children.

2.2. Study design

Data was collected through qualitative ethnographic research conducted by the first two authors (PK and SB); they carried out fieldwork for 4 and 9 months respectively between 2010 and 2012 (the first author [PK] also undertook a survey to assemble quantitative material, which will be reported elsewhere). The main methods of data collection were in-depth interviews with children and participant observation in homes of HIV+ children, in post-test clubs, and in treatment centers. Conversations were held with caregivers and health care providers as well.

2.3. Study participants and selection criteria

The study was undertaken among HIV+ children selected from the 9 health facilities that provide ART in Jinja District. A total of 35 HIV+ children aged 8–17 years on ART who had been identified and screened for eligibility with the help of health care providers were followed up. The 35 children were purposively chosen to include different ages, sex, family situations/caregiver category, education levels, membership in post-test clubs and disclosure status. Four of the children were not aware that they were infected with HIV. The children's median age was 12. The majority were in primary school; about two thirds (24/35) had lost one or both parents and only half of them (18/35) were living with a biological parent (Table 1).

While there was an almost equal number of boys and girls receiving treatment in the survey that preceded the ethnographic study, most of the caregivers were female. Even where male relatives including fathers were present in the homes, children's communication about their health and medicines was gendered as they tended to communicate more with female caregivers. During visits in homes and at the treatment centers, we interacted more with female caregivers and found them better informed about issues relating to the children's health and medicines.

2.4. Interviews with children

An interview guide was used to interview 21 HIV+ children aged 11–17 years. The open interview started off in the form of an everyday conversation about their social worlds (home, school, friends, relatives, daily activities and interesting things about their lives). Once the child was comfortable, the researchers turned to their experiences with regard to their health and medicines exploring their understanding of health and of the medicines, who they communicate with most about their health and medicines in different places and their experience of having to take medicines daily. The first author (PK) who conducted the interviews was conversant with the local languages (Luganda and Lusoga) spoken by the children. The children either spoke Luganda, Lusoga or English; the languages used in all the interviews/conversations with the children. The interviews, which lasted 40–45 minutes, were audio recorded (with participant permission), transcribed and translated into English.

Two graduate research assistants (a male and female) experienced in qualitative research and conversant with the three languages worked with the researcher. Before the interviews were conducted, PK visited the homes of the children several times accompanied by the research assistants who acted as guides to the homes during the initial visits and helped to get familiar with the families and create rapport with the children. The goal was to create a comfortable environment for the children and encourage them to openly and freely talk about their lives. Efforts were made to minimize power differentials that would intimidate the children. Once the children were comfortable with the researcher, PK visited the homes unaccompanied and conducted the interviews. The research assistants transcribed and translated the recorded interviews into English. Transcripts were cross-checked and verified by one of the research assistants and the first author for consistency and accuracy.

2.5. Participant observation

Participant observation in the homes of the HIV+ children, at treatment centers and post-test clubs was a key strategy for collecting data. The researchers made several visits to the homes of the 35 children and interacted with them, their caregivers and other family members. One of the researchers (SB) lived with one of the families for three weeks, which provided insight to the daily life and challenges of the family.

During visits to the treatment centers on clinic days, observations of the interactions and communication between the children, health care providers and caregivers were made in the waiting area, counseling/consultation room, pharmacy and other places. In addition, the researchers participated in some administrative work in the consultation room and got well acquainted with the procedure followed and patterns of communication right from the waiting area to the pharmacy dispensing area.

The researchers also carried out observations at post-test clubs of HIV+ children, where they attended health education sessions, listened to discussions and observed interactions and communication between children during shared meals, games, music, dance and drama.

2.6. Data analysis

Data comprised transcripts of in-depth interviews and detailed field notes taken during conversations in follow-up visits and observations in the different places. Preliminary data analysis occurred concurrently with data collection especially during quarterly meetings, PK and SB had with the co-authors to update them of progress, share insights on emerging issues, which also informed plans for further data collection.

The process of typing and reading through the transcripts and detailed field notes helped to draw attention to emerging themes and was an important part of preliminary analysis and identification of thematic categories. A list of themes was generated as part of the process that formed a framework for a code book. The research objectives and topic guide (used during in-depth interviews) also guided the generation of the code book.

There were 20 major themes that were derived from the thematic analysis and under each were sub-themes that ranged from five to thirty. The major themes included children's socio-demographic characteristics; family relations/situations; other significant relations; visits to treatment centers/experiences; experiences with medicines; awareness about illness; child's communication about medicines and illness/health (at home, school, neighborhood, treatment centers, other places); category of people/person most talked to about illness and medicines; communication by other people about child's health and medicines; advantages and disadvantages of discussing one's illness and medicines; challenges and concerns of being on ART, challenges and concerns of having HIV/AIDS; person most talked to about challenges/concerns; suggestions on support to live on life-long medicines (ART); people's awareness of child's illness and medicines in different social spaces, disclosure/non-disclosure in families; recommendations on disclosure; involvement and communication about sexual relations; and other important experiences in child's life. Additional sub-themes that emerged from the data were also included.

The compiled data set was eventually imported into ATLAS.Ti.version 7 (ATLAS.Ti.Scientific Software Development, Berlin Germany), which was used to more systematically manage, code and retrieve data. As part of the coding process, segments of data that related to the themes were identified. The process involved reading through the imported data file that represented a child/case and field notes, identifying relevant sections/segments of the text passages and assigning relevant codes to them using the code manager. In addition "memos" that contained thoughts about the selected segments were written. Together the codes and memos formed the basis for the thematic analysis where patterns and meanings to the codes were established. Through this process the large data set was condensed enabling the identification of recurring themes, linkages and similarities. On the basis of this, impressions were developed and eventually explanations and arguments.

2.7. Challenges of working with children

A major challenge of working with HIV + children was the sensitive nature of their health and the need to control information, especially where we were not sure what the children knew. During visits in homes, caregivers were usually present and this sometimes interfered with the flow of the conversation with the children, who tended not to speak freely in their presence. At the same time, the children seemed reassured by having these familiar adults nearby, especially at the first visit. Adolescents preferred meeting us away from home where they felt free to share issues that they did not want their caregivers to know about. Although part of our interest was to interact with them in a home setting, we had to comply with their wish.

The researchers exercised maximum precaution during the interactions with children to avoid unintended disclosure. Children were not asked about HIV/AIDS but instead were asked about their health and medicines. The researchers were careful to let the children lead in conversations and did not push them to reflect on matters for which they were not prepared. They were also sensitive to whether the child wished to move from medicines to other aspects of illness and treatment. The issue of medication was a good pivotal point because it involved a daily practice in which all children engaged. Indeed, it turned out that communication about medicine was easier than talking about HIV.

Throughout the study, the researchers worked closely with specialized pediatric counselors from each of the 9 treatment centers where HIV + children were receiving treatment in order to ensure support and specialized counseling services to children when need arose.

2.8. Ethical considerations

Ethical clearance to conduct this study was obtained from Makerere University College of Health Sciences, Higher Degrees, Research and Ethics Committee and the Uganda National Council for Science and Technology. Permission was also obtained from treatment centers where children on ART included in the study were accessed. The purpose of the study was explained to the caregivers and their children. Written consent was obtained from caregivers and written assent was obtained from HIV + children whose caregivers had provided consent. Only children 8 years and older were followed, since according to Ugandan ethical guidelines that is the age of assent. To ensure confidentiality, we have used pseudonyms.

Ethical guidelines instruct us to keep participants' information confidential, but there were times when we experienced ethical dilemmas arising from children's revelations about behaviors that obviously put their health and welfare at risk. For example, there were children who confided that they were throwing away the medicines because they did not know why they were being forced to take them; others reported that they only took their medicines when their caregivers were present. Children especially double orphans, confided experiences of verbal abuse and discrimination from caregivers. Some revealed that they were made to do a lot of manual work even when unwell, denied food and forced to continually take medicines on empty stomachs. Adolescent girls shared experiences of engaging in unprotected sex with multiple partners including HIV + peers and their caregivers were unaware. Children also expressed emotional their caregivers disclosed their status in the neighborhood or at school. Caregivers reasoned that they informed school authorities to protect children from harsh punishments and to enable children to absent themselves when unwell or when they had to keep appointments at treatment centers. Children felt this was stigmatizing and interfered with their rights to privacy. In such cases, we felt it necessary to breach confidentiality and report these alarming situations that were putting children's health at risk to pediatric counselors who addressed the issues with caregivers expeditiously.

The poverty situation observed in most homes necessitated that on the follow-up visits that we carry gifts like a bar of soap, a kilo of sugar or food items. When the children or family members fell sick, we contributed financially to help them with transport to hospital or to buy food. It was difficult for us to ignore critical needs.

2.9. Conceptual framework

We draw on the concepts of children's places, children's agency and information control to analyze communication practices of HIV + children in homes, post-test clubs and treatment centers.

The concept of children's places invites us to investigate children in relation to place, understood as both social position and physical location. Olwig and Gulløv argue that in most societies there are places for children and places where children will rarely be seen (Olwig & Gulløv, 2003). They explain that places frame different kinds of social meetings, opportunities, and children's movements; and they suggest that we analyze how children use places.

The concept of "children's places" is particularly relevant in our study because during the time the researchers spent in homes, post-test clubs and treatment centers, it was clear that the physical places correlated with the social placement of children. They influenced the kind of interactions children had in the different places and consequently their communication practices regarding their health and medicines.

We draw on the concept of "children's agency" from the growing field of the anthropology of children; this emphasizes that children are not passive subjects of social structures and processes (James and Sprout, 1997). Children are social actors, have agency and must be seen as active in the construction and determination of their own social lives, the lives of those around them and the societies they live in (Bühler-Niederberger & van Krieken, 2008; James, 2007; Tates et al., 2002c). We show that despite the subordinate position children occupy in the generational order, they expressed their agency by using the possibilities in the different spaces to express their feelings and choices with regard to their health and medicines.

Inspired by Goffman, we analyze information control. We show how caregivers, health care providers and the children deliberately refrained from direct conversation about the disease because of the negative attribute it carries. Goffman used the term stigma to refer to an attribute that is deeply discrediting (Goffman, 1963). As a result, individual and social identities are spoiled and the stigmatized person incorporates a negative view of the self. Goffman states that because of stigma a family may constitute itself into a protective capsule for its young. Within the capsule, a congenitally stigmatized child can be carefully sustained by means of information control (Goffman, 1963). His concept of stigma fits well with existing studies on disclosure and with our findings, which demonstrate that because of the stigma associated with HIV and its modes of transmission, secrecy often surrounds the diagnosis (Abadia-Barrero & Larusso, 2006; Heeren, 2011; Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008; Vaz et al., 2010).

3. Results and discussion

Table 1
Demographic characteristics of HIV positive children.

Characteristic	Frequency (n = 35) (%)
Sex	
Male	17 (49)
Female	18 (51)
Age	
8–10	5 (14)
11–14	19 (54)
15–17	11 (32)
Caregiver category	
Lives alone	3 (9)
Both parents	8 (23)
Biological mother	6 (17)
Biological father	4 (11)
Grandparent	11 (31)
Other relatives (aunts, uncles)	2 (6)
Institutional home	1 (3)
Orphan status (n = 24)	
Single orphan	10 (29)
Double orphan	14 (40)
Level of education	
Primary	19 (54)
Secondary	7 (20)
Out of school	9 (26)

3.1. Communication patterns of HIV + children in homes

Communication in homes was influenced by the hierarchical structure of relations in the families. This was evident in our attempts to draw children into conversation when caregivers were present. Despite the fact that caregivers knew that our interest was in the children, they took the lead in all the conversations and children only talked when asked specific questions. Children did not spontaneously join in the conversations even though they were about them. During visits to the home of Helen, an 11-year-old girl who lived with a grandmother and an uncle, it was difficult to get any response from Helen when her caregivers were present because her uncle would talk for her. However, in their absence, she opened up and conversed freely with us.

This hierarchical communication pattern was especially strong in homes where children had not been told their HIV diagnosis. In some homes children were only allowed to greet us and then sent away. There were cases where caregivers took us aside and requested us not to mention HIV/AIDS or ARVS in our conversations with the children. On arrival in one of the homes where both parents and two of the four children (Robert aged 11 years and his 15-year-old sister) were infected, the mother took us aside, explained that the rest of the family members were not aware of their sero-positivity and so there was no open discussion about their status in the home. According to the mother, the medicines were kept in their bedroom where all the medicine-taking and communication about medicines and health took place. She explained further that the children had been cautioned never to mention anything about their status and medicines. Therefore, even within homes, there were certain places (sub-places) as opposed to others, which were deemed appropriate for talking about HIV and taking medicines as illustrated above.

During our first visit to the home of Farouk (age 9), his grandmother met us a distance away from home and told us her struggles with forcing Farouk to take medicines and also to go for the monthly refills of ARVs. As we walked to their home, she requested us to refer to Farouk's sickness as “musujja” — malaria or fever. She explained that her grandson was too young to be told that he was suffering from AIDS. During the conversations, Farouk was only allowed to greet us and sat silently listening as the grandmother narrated his persistent bouts of malaria, coughs, skin rashes and lack of appetite. She deliberately averted Farouk's participation in the conversations and talked for him. However, in one of the subsequent visits, when his grandmother excused herself and went to the kitchen, PK asked Farouk why he was taking the medicines. He said he did not know why he was being forced to take them but that he had heard people at the hospital call the medicines “RVs”, although he did not know what it meant. When the grandmother came back, Farouk immediately kept quiet and never talked during the rest of the visit.

Children's own descriptions of communication with their caregivers suggested that it was directive and limited to taking medicine. They were questioned, “Have you taken your medicines?” and reminded, “if you don't take your medicines, you will die, medicines are you life.”

Irrespective of age of the child and category of caregiver, most of the communication in homes revolved around medicines rather than the HIV diagnosis. For example, Agnes (12 years) never talked about AIDS with her grandmother. Interactions with her revealed that although she had been disclosed to, she did not know what “AIDS” meant. When the topic arose, it was discussed in relation to taking medicines:

> Interviewer: What does your grandmother say about this disease of AIDS when you are discussing with her?
> Agnes: Say about it?
> Interviewer: Yes. When you are talking with her, what does she say about it?
> Agnes: She emphasizes to me the importance of taking medicines. She tells me to take the medicines without missing, that if I miss I will be destroying my own life. She says such things, and then I take the medicines.

Similarly, Vaz and colleagues noted that medications featured prominently in disclosure discussions between parents and the infected children as an entry point to full disclosure, as part of the description of the illness, or as part of the advice given to the children on how to act (Vaz et al., 2010). Abadia-Barrero and Larusso (2006) identified medications as the AIDS symbol most commonly used to relate to the daily activities around care among HIV + children and youths living in an AIDS institutional home in Brazil.

Ugandan caregivers perceived their children as being too young to understand their diagnosis and to keep it secret. They refrained from using the word “AIDS” in their conversation with the children and even when they did disclose after pressure from the children, the latter were sworn to secrecy in an effort to control information. For example, 8-year-old Twino who lived with a twin brother, and had other siblings and a father who were HIV negative, kept asking his mother why only the two of them were taking medicines and when they would complete the dose. The mother got tired of the questions and explained to him that they were suffering from a disease called “slim.” He asked her what it meant and how they contracted the disease. She told him that she did not know where they got the disease and swore him to secrecy. In this regard, caregivers sternly instructed their children never to tell anyone about the diagnosis. One caregiver, a mother of three children, threatened them that if they ever revealed the secret, it would result into her death, leaving them orphaned. In such situations, children's questioning and curiosity should have provided caregivers with an opportunity to have a dialogue about the disease and treatment but this did not occur. The hierarchical environments in the home and to some extent at the treatment centers, along with the forces of stigma and the secrecy associated with AIDS, all led to children silencing many of their questions.

This lack of open communication about HIV/AIDS between children and adults was also due to caregivers' fears of the impact of such discussion on the children. Like many others, Helen's caregivers pointed out that they were afraid that she would lose hope if they spoke about such matters and were therefore very protective and careful when they talked with her about her health. Caregivers may underestimate children's ability to understand and deal with issues related to their health.

Our findings showed that in almost all the homes, there was silence about HIV/AIDS even where disclosure had taken place; the sickness itself and its implications were not discussed. Our findings showed that children had questions but they were forced to keep these questions to themselves. The only communication was about medicines: at medicine taking times caregivers reminded children to take their medicines or asked whether they had taken them.

The controlling of information by caregivers may also be attributed to the intimate connection between HIV/AIDS and the local moral conception regarding sexuality, care and parent–child interaction in Uganda (Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013). Kyaddondo et al. (2013) explain that open discussion with children on matters related to sexuality is not culturally sanctioned and that the fear of explaining how one became infected places parents in a dilemma. This makes it difficult for parents, especially mothers, to inform their HIV-infected children about their sero-status as observed in our study.

Yet our findings concurred with others that children did not just accept communication constraints but expressed agency in different ways (Baarøy, 2002; Meinert, 2009; Onyango-Ouma, 2001). Although caregivers' authoritarian control over the children constrained children's discussions about their diagnosis and medicines, many of them developed other strategies to get answers to their questions. Children expressed their agency in different ways, which included resistance strategies like silence, refusal to take medicines and repeated questions. Some also used these same strategies as a leverage to have their needs met. Most of the children took the medicines without questioning at first, but when they realized that it was a daily practice, they repeatedly asked their caregivers questions like, "why am I taking the medicines?, when will I stop taking the medicines, what are the medicines for? why is it only me taking the medicines" Stella, who came from a very supportive family, threatened to stop taking medicine, demanding an answer from her mother who refused to tell her, afraid of the impact it would have on her.

> At first I did not know, I always asked myself why I was taking medicines and I thought maybe every child is like that. I was just being forced to take medicine. I used to fall sick frequently and the doctor would come and put drips on me at home. They were talking about malaria and I thought maybe it is malaria that is making me be put on drips. I asked my mother but she was always twisting things around. So, I went to the doctor and told her that I take a lot of medicine and I am fed up with it. The doctor told me that I shouldn't stop taking medicines; that I should take the medicines daily because I have AIDS. I felt bad and feared and got annoyed! (Stella, 14 years).

Even the 8–10-year olds, who were thought to be too young to understand the magnitude of the diagnosis and to keep it a secret, repeatedly asked similar questions. Derrick (10 years) and Yusuf (9 years) repeatedly asked their grandmother when they would recover and stop taking medicines. It was not until the grandmother explained to them that they were taking medicines for lung infection and that it was the health care providers who would decide when they would stop, that they let off asking questions. The grandmother did not allow us to talk to the children alone. She explained that during visits to clinics, she controlled interactions between them and the health care providers for fear of inadvertent disclosure.

Although the communication hierarchy and control of information silenced children's persistent questions and curiosity, they sought alternative sources of information to their unanswered questions and unexpressed concerns. Children found other people to talk to when their caregivers closed off. Stella reported that she had concerns she wanted to tell PK, which she had never told anyone, even her mother to whom she was very close.

> My family really loves me and they have been very supportive, they don't want me to get worried although sometimes when I am alone I can't help worrying though I never tell them. For example, I keep asking myself that why is it me who is infected and not my sisters? I envy them because they don't have to take medicines everyday although I have come to terms that I will have to be on these medicines for the rest of my life. The truth is that there are times when I am so fed up of these medicines. In the past, I would ask my mother that "why am I taking medicines? When will stop taking medicines?" You see, I must be strong to show my family that I am grateful and I appreciate their support. I do not tell anyone these challenges, not even my mother.

As observed by Onyango-Ouma (2001) in his study on children and health communication in Western Kenya, the modes of action children used to deal with constraints on communication depended very much on the type of social environment in which they were situated as actors.

However, almost all the children withheld information about their diagnosis and medicines outside clinic settings for fear of being gossiped about and discriminated. The fact that children withheld information demonstrates that their need for open communication was limited and circumstantial. Our findings revealed that children usually demanded open discussions about their medicines or diagnosis because they were forced to take medicines daily and make repeated visits to treatment centers without understanding why. Like Stella, they asked caregivers to explain why they had to do these things even when they were feeling well.

3.2. Communication patterns at post-test club meetings

In contrast to the hierarchical structure of communication patterns in homes, post-test club meetings were more egalitarian and child-centered. Observations at the 10 post-test club meetings we attended and interactions with health care providers revealed that older children participated in the formation of the post-test clubs, formulation of club activities, expectations and selection of club leaders. Children were in control of the activities, facilitated some of the sessions and were encouraged to ask questions and participate freely in education sessions. The facilitator played the role of guiding the discussion and would be helped by club leaders to keep order during the discussions. Most but not all children talked about HIV when they had to, during the structured sessions, but refrained from doing so during other activities. Boys tended to be more proactive than girls and would take the lead in most sessions.

Post-test club meetings consisted of 2–3 structured sessions, which were participatory and learner-centered. The first session involved only children and was facilitated by one of the club leaders. It involved participatory recap of previous club activities and brain-storming on future activities. This was followed by a health education session facilitated by health care providers or club leaders and it involved activities or discussion on topics selected by children. Topics included issues that were pertinent to children's lives including challenges they were going through and were not exclusively focused on HIV/AIDS or medicines. They discussed positive living, nutrition, hygiene, discipline, sex, relationships, pregnancy, abortion and other reproductive health related issues. During the discussions, children highlighted challenges and brainstormed on solutions. During other sessions, children selected a novel, read some of the chapters in turns and then discussed it guided by a facilitator.

The third session involved shared meals, games, music, dance and drama. Children practiced skits, poems and songs that they presented in outreaches to schools or during ceremonies at the treatment center. Outreaches to schools were a new activity and were conducted once a month. During the outreaches, children presented songs, skits, poems, dances, drama and testimonies after which facilitators encouraged children from the host institutions to ask questions, provided voluntary counseling and testing and refer those who needed further services to the treatment center.

At one session the topic discussed was adolescent sexuality and the increased cases of pregnancy among girls in the club. The session was facilitated by the male club leader and was attended by 20 HIV+ children (10 boys and 10 girls) aged 13–17 years who were seated on plastic chairs in a circle under a tree. Although the leader was very serious when communicating concern about the increasing number of pregnancies among the girls, the adolescents kept giggling, making fun of the issue. In opening the discussion, he communicated that the 5 girls who were pregnant ignored information given about the dangers of being pregnant when HIV+ and on ART. He then asked the group for possible causes and solutions to the problems. The discussion was very lively and interactive.

The egalitarian tone was evident in the way Club members responded to their leader's attempts to be directive with banter and objections.

Box 1

Discussion during a post-test club session.

Boy: There is too much freedom for some girls. By the way, when girls go to discos, is it the disco or music that makes them pregnant or something else? (Laughter)

Girl: During counseling, they should not use parables but call a spade a spade. The counselors should be frank and point out explicitly how one gets pregnant.

Club leader: In case any of you Club members realizes that you are pregnant even after one day, you should keep away until giving birth and after that if your husband allows you, you can come back.

Girl: Don't bother asking anyone whether she is pregnant or not because we won't answer you.

Girl: What does the Club constitution say about pregnancy?

Club leader: It says that when one gets pregnant, they should enroll on PMTCT, continue coming for treatment but shouldn't come back to the club.

Girl: Some girls come from needy families; they admire material things and end up succumbing to men who can provide for them and in the process they don't think about protected sex.

Boy: But some girls sleep with multiple partners and they might not know who the father of the child is.

Boy: But getting pregnant doesn't take 30 min.

Club leader: Children in the Young Positives Club are sexually active, including you boys! (Giggling)

Boy: For me when I am going to sleep with a girl, I tell her that I am castrated and she gives in. (Laughter)

Club leader: Most of you are in school and should be focused on your studies even amidst temptations. There are many children who are out of school because of lack of school fees. So I would advise you to make good use of the opportunity you have.

In general, post-test clubs provided enabling environments for children to talk about issues of interest to them in addition to health and treatment related topics. Children felt secure to communicate freely, as one girl explained:

> During holidays, I spend most of the time at the Young Positives Club because I feel happy whenever I am among children who are HIV+. That's where I belong among fellow positives. At the Club, we discuss, counsel ourselves especially concerning how we are treated at home. I get along so well with my fellow positives. We are like relatives because we have the same problem and when we share among ourselves, we realize we go through similar experiences (17-year-old orphaned girl).

Our findings echo Goffman's observation that a stigmatized individual will find sympathetic others who are ready to adopt their standpoint in the world and to share with them the feeling that they are human and "essentially" normal in spite of appearances and in spite of their self-doubts (Goffman, 1963). Goffman explains further that the sympathetic others, knowing from their own experience what it is like to have this particular stigma, can provide the individual with instruction in the tricks of the trade and with a circle of lament to which one can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who is really like any other normal person.

The ease of communication in the clubs was in sharp contrast to children's feelings about communication in other settings. They felt uncomfortable in environments like schools, where there was open discussion about AIDS among "non-initiates". They explained that they did not want to be told that they had AIDS. They found the word insulting, abusive and condemning. Matthew had this to say on the issue:

> I don't want them to abuse me by telling me that I have AIDS. We hate to be told by other people that we have AIDS. It hurts me because it's not me who got myself infected (Matthew, 11 years).

Acknowledging one's status was not a problem among "insiders" at the Club, but hearing it from "outsiders" felt like abuse. Where AIDS belongs to an embarrassing private world and becomes a shameful characteristic (Abadia-Barrero & Larusso, 2006; Goffman, 1963), the post-test club is an oasis where one does not need to worry about controlling information.

3.3. Communication patterns at treatment centers

At treatment centers, children's places ranged from rather subordinate and peripheral to more equal and central. We observed that in all treatment centers there were elements of both hierarchical and egalitarian communication patterns. Health care providers tended to be rather authoritarian and spoke mostly to caregivers when they were present, whereas some who were trained as counselors tried to be more child-centered in their communication.

HIV+ children who participated in our study were selected from 9 treatment centers, which comprised 3 private not-for profit and 6 government health facilities. There were 3 different categories of children's clinics offered by the treatment centers. The first category consisted of 5 treatment centers where adults and children were mixed and attended the same clinic days. The second category consisted of four treatment centers that held clinic days twice a week for children. Out of these four in the second category, two conducted an adolescent clinic day once a month for children aged 12 years and above, forming the third category.

In all the 9 treatment centers, the same procedure was followed in attending to children. On arrival at the treatment centers, HIV+ children or their caregivers would sit outside on benches in a sheltered place that acted as the reception and as soon as the clinic opened, they gave in their books where information about their health and treatment was recorded on each visit. The books were arranged on a first come-first serve basis. As soon as the health care providers (counselors) were ready, they called in the children one at a time starting with the one who arrived first. In the non-government treatment centers, each counselor sat in a private room where they attended to each child in private. Government health facilities, on the other hand, lacked space and the few (2–3) counselors attended to the children in one room, which was usually small, congested and lacked privacy.

Many of the younger children were accompanied by their caregivers who took the lead during consultations with health care providers. In the consultation rooms, health care providers (counselors) asked questions about the child's health and treatment, most of which were answered by the caregivers even when the question was directed to the child.

From the consultation room, the books were sent to the clinician/doctor's room where the children were called for further examination. Even at this stage, it was the caregivers who responded to questions even when they were directed to the child as observed below during a doctor's session with Shakirah (13 years) and her mother:

> Doctor: Shakirah, how are you and how have you been?
> Mother: Doctor, we are fine, but Shakirah has been so sick and even missed end of term exams.
> Doctor: That's not good news. Shakirah, what are you suffering from? What is the problem?
> Mother: She fell sick two weeks ago and they were treating her for malaria and her condition was not improving. She was being treated in a clinic near home. I got so worried, her temperature was going up and she had a painful headache until they tested and found out that it was typhoid. I feared she was going to die. She even has wounds in her private parts. The wounds keep on coming and going.
> Doctor: Ok, so now, how are you feeling?
> Mother: She was admitted for two weeks. They first put her on water drips during the first week but the temperature was not decreasing and when they found out that she had typhoid, she was put on half drips of Cipro, 3 of them. They couldn't give her full drips because they were too strong for her. But even with the 3 half drips of Cipro, she is feeling dizzy and weak as you can see.

Although, no studies on children's participation in medical consultations have been done in sub-Saharan Africa, our findings are in agreement with studies from the Global north (Cahill & Papageorgiou, 2007; Tates & Meeuwesen, 2001). These studies concluded that parental speaking for the child is institutionally co-constructed; parents take responsibility, which is hardly ever questioned by children, and general practitioners ratify this behavior by refraining from meta-communicative comments and by aligning with the parent in the course of the interaction (Tates et al., 2002a; Tates et al., 2002c).

Even when a caregiver was not present, the social hierarchy, with authority vested in the health care providers, influenced children's behavior and communication practices. Helen, like many of the younger children kept a low profile at the treatment center. Most of the younger children, including Helen, would either sit down if there was space available on the benches, or stand leaning against the wall as they waited for their names to be called. During consultations, Helen (like most of the younger children) politely answered the questions asked by the health care providers if her caregiver was not present, but a dialogue with her, where her opinion and feelings (concerning her health and treatment) was central, would rarely happen. Helen's norms of communication and the limited time available for each child at the heavy clinic were not conducive for child-centered communication as illustrated below:

> Doctor: Open your mouth. Where is your grandmother?
> Helen: She is sick.
> Doctor: How long have you taken without taking our tablets?
> Helen: I have taken two days. Sometimes I forget to take the medicine.
> Doctor: You should take the medicine because it is your life and you are hurting it when you don't take the medicine.
> Doctor (to SB): She is so forgetful.
> Doctor: If you don't take the medicine, you will get sick and die.
> Stine (SB): She is so forgetful?
> Doctor: Yah, at times she forgets and she has no one to remind her.

From the doctor's room, children who needed further examination were sent to the laboratory but most were sent to the dispensers for their medicines. Interviews with children revealed that most of the time, doctors/clinicians just asked them if they had any sickness and if their response was “no”, they were instructed to proceed to the pharmacy.

Communication with the dispensers was more authoritarian than egalitarian, with instructions being given on how to take the medicines and cross-checking if the medicines were being taken as prescribed. In cases where children had missed taking some doses, the dispenser and health care providers were stern with them and their caregivers, warning them of the consequences, and in almost all cases disregarding the reasons given for not taking the medicines. For example, on one of the clinic days, a 13-year-old boy who was found habitually not taking some doses, was confronted by the dispenser and a counselor with the aim of finding out the cause and the solution to the problem.

> Dispenser: What is your balance? (Josef gives him the medicines).
> Dispenser: When were you last here?
> Josef: One month ago.Dispenser: We told you to take 2 tablets twice a day. Why do you have so much medicine left?
> Josef: I take one in the morning and one in the evening.
> Dispenser: There are also some tablets left in the other tin. So you don't take your medicines as you should?
> Dispenser: With whom do you live?
> Josef: My mother.
> Dispenser: You have to take your medicines otherwise you will fall sick.
> Health care provider (shakes her head, raises her voice and talks sternly to Josef): Your young brother is also on ARVs. You should be responsible for reminding him to take his medicines instead of the other way round!

The dispenser adopted a more child-centered approach, motivated the boy to take medicines as instructed and explained that he would fall sick. The health care provider, on the other hand, reprimanded the boy, shamed him about his position as big brother, and assumed that his mother's authority was necessary to make him obey.

Older children were able to ask health care providers questions. Through their monthly visits to the treatment centers, they were observed to have created friendly relationships with peers and with the health care providers and some gave practical assistance in running clinics and also talked to other children. Practical assistance involved receiving books from children and caregivers as they came in, looking for their record files and calling them in to see counselors when their turn came.

Three treatment centers constituted the third category of clinic, namely “the adolescent clinic” held once a month for adolescents aged 12–18 years. Communication between older children and the health care providers was friendly and the relationship seemed less authoritarian. The authority of the health care providers was not always evident in the communication between them and the older children, but when a “conflict” arose, authority was exerted. Adolescents had favorite counselors/health care providers whom they preferred to confide in and felt comfortable talking to.

Activities on the adolescent clinic days were a mixture of those done during the normal clinics for children and post-test club meetings. The first session involved informal interactions among children but at one of the treatment centers, the children had an organized session, which was participatory and involved an interactive discussion of issues of their own interest like sex, relationships, dating. The second session was more structured, facilitated by health care providers and it involved discussing a health education topic of interest to the children similar to those addressed in post-test club meetings e.g. positive living, life-skills, self-esteem, how to avoid infecting partners and getting re-infected by others with HIV. In one of the treatment centers, children were divided in 3 age groups (12–13, 14–15 and 16–17 years) and given topics to discuss tailored to their age. The last session involved informal interactions among children, lunch or snacks, after which they went through the normal procedure on clinic days of individual sessions with counselors, doctors and the dispenser. Then they would go home in groups as they talked and laughed.

Adolescent clinic days, like post-test clubs provided enabling environments for children to talk about issues of interest to them. The adolescents always looked forward to their clinic days with anticipation to meet their peers and to socialize. They explained that they enjoyed meeting their fellow HIV + children because they considered them to be their best friends. They described them as understanding because they shared the same problems and experiences with medicines.

4. Conclusion

Using the concept of “children's places” as a framework to analyze communication practices of HIV-infected children, our findings showed that whereas children were able to express themselves freely at the post-club meetings and to some extent at the treatment centers, their communication in homes was constrained due to the social hierarchy. Our findings challenge the universality of Article 12.1 and 13.1 of the United Nations Convention on the Rights of the Child, which call for freedom of expression (UNICEF, 1989). The two articles do not take into account the complexity of the different cultures and norms that exist in the different parts of the world, which facilitate or constrain children's verbal expression. In traditional African settings, young people are considered to be dependents under the responsibility of caregivers and consequently their verbal expression is constrained by the hierarchical structure in families.

Furthermore, whereas Article 17 of the UN Convention on the Rights of the Child states that every child should have access to information and material from a diversity of national and international sources especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health, our study illustrates that some children do not know their HIV status. Our findings showed that controlling of information about HIV/AIDS ran through all the three places but was more pronounced in homes and to some extent in treatment centers. Communication in homes was constrained by adult perceptions that children should not be told that they had HIV until they were 12 or 13 or until they were deemed old enough to understand. For older children, communication about HIV was easier at post-test clubs and treatment centers but constraints existed even there. This control of information is contrary to the Uganda National Policy on HIV Counseling and Testing (2005), which instructs provision of information on HIV diagnosis and ART to children as they grow older or improve on treatment (Ministry of Health, 2005). Blasini and colleagues noted that there are cultural differences in the amount of information given to patients about their illness, especially children and in managing emotionally charged topics in general. They point out that open discussion may not be a typical strategy when coping with illness and death (Blasini et al., 2004). This is further explained by Bowman (1997) who contends that western biomedicine principles tend to neglect the substantial differences in the way people of different cultures perceive, experience and explain illness because of a biomedical focus that neglects the context of the situation. Bowman (1997) explains that western bioethicist place a high value on truth telling, yet in the face of serious illness many non-western cultures believe that giving negative information may induce negative outcomes (Bowman, 1997).

Children's participation in communication about their health in homes and treatment centers is an understudied topic in our settings. Focus has been on disclosure and caregivers and health care providers' concerns and dilemmas on whether, when and how to disclose HIV diagnosis to children. Tates and Meeuwesen (2001) noted that there are theoretical as well as clinical indications that the child's role in medical conversation deserves special attention. They point out that children appear to be able to understand more about concepts of health and illness than has been generally assumed.

Our study illustrates that homes, where most of the treatment and care-giving takes place, are enabling in terms of care but not so in terms of communication. This is why children sought other places for answers to their unanswered questions and to voice previously unexpressed concerns. Our findings suggest the need to take into consideration the communication hierarchy of homes, to target parents' communication skills in HIV programming, and to develop interventions to help caregivers communicate messages about diagnosis and ART to HIV + children.

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